

Financial Planning

Special Needs Clients: 'Retirement for 3'

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More than 5% of school-age children are diagnosed with a disability - difficulties with seeing, hearing, talking, walking or thinking. The burdens of caring for these children can be overwhelming, and require a lifetime of planning, financial and otherwise.

Besides health care, these children often need behavioral therapy, physical therapy and special schooling. And their families may need extra help in paying for this care - not just when the children are young, but as they grow into adulthood, and after the parents die.

Advisors warn that planning for lifetime care is a complex process that should involve a team of legal, health and financial professionals. In some cases the children may take part, too, depending on their ages and abilities.

"We're not just doing the planning for the parents, but for after the parents or caregivers may be gone, up to 40 years into the future," says Jerry Hulick, senior planner at the Washington Group Special Care Planning Team in Fairfax, Va.

OVERWHELMED PARENTS

Often the first hurdle is getting parents to think about planning their finances as they relate to their child. Because parents are often overwhelmed, bringing them on board as clients might be a lengthier process than usual. "Most typical estate planning cycles, it could be up to three months or so. In a family with a disability, it could be a year and a half," says Joanne Gruszkos, director of the Special Care Program at Mass Mutual Life Insurance in Springfield, Mass.

Ask delicate questions up front, say advisors. "There are all these emotional dynamics you have to get through before you get to the technical questions," says Mary Anne Ehlert, president of Protected Tomorrows, an advisor network in Lincolnshire, Ill., that helps families caring for disabled members.

Advisors should find out what the parents expect for their child and what kind of life they envision. Will the child likely have a shortened life span? Will the child be capable of working or living independently? The answers will inform the direction of the family's plan.

Families with disabled children often struggle with financial issues. Medical, therapeutic and emergency health care costs can sap a family's bank account.

Such parents may also have neglected their own retirement funds. Or a family may need to rework its plan when a young adult becomes permanently ill or injured. That makes retirement planning the next priority, Ehlert says, to take into account that the parents' costs of living in retirement could be higher than the norm. "I call it retirement planning for three," she says.

Moving to a city with a lower cost of living might not be practical if programs or treatments for the disabled person aren't available. Downsizing to a smaller home might also be off the table.

Most advisors recommend a more conservative portfolio. "If they're thinking about retiring, you might suggest they lower the amount of money in equities," she says. "That becomes more so if you're dealing with a special-needs child. The family bucket has to be a conservative pot. You have this extra liability cost." As a general rule, she suggests a fixed-income allocation that's 10% to 15% higher than what would ordinarily be appropriate for a couple near retirement with no disabled children.

FOCUS ON ELIGIBILITY

To be eligible for many government programs and benefits, including Medi-caid and Social Security's Supplemental Security Income program, a disabled person can't have more than \$2,000 in assets, subject to a five-year look-back period. Once an impaired person ceases care from his parents, it's crucial for an advisor to ensure the child doesn't have assets in his or her name that would disqualify that aid.

"A planner will want to make sure [children are] not listed as beneficiaries on trusts, wills, group health plans, 529 accounts - all of that would be considered disqualifying," Gruszkos says. The same holds true for 401(k)s or pensions.

Planners urge even wealthy families to keep assets out of a disabled child's name, because some benefits, such as certain Medicaid programs, don't accept private payments. Even a large pool of money might not cover out-of-pocket health care costs. "We run into situations where they're independently wealthy and say they don't need to use government benefits," Hulick says. "I had a case where a family set up a \$10 million trust. Because she had no health coverage and [had] money in her name, within 11 years they went through the \$10 million."

SPECIAL-NEEDS TRUSTS

Planners often recommend that families set up a third-party, special-needs trust, which should be handled by an experienced lawyer. Assets in these trusts aren't counted toward the disabled person's eligibility cap for Medicaid benefits, but there are rules about how that money can be used, says Dennis Sandoval, an estate planning attorney in Riverside, Calif., who works with the Special Needs Alliance, an advocacy group.

"Cash is always bad," he says. "If you have a special-needs trust and the trustee gives the beneficiary cash, that cash counts against their benefits, dollar for dollar."

Unearned income set aside for food and shelter expenses - called in-kind support and maintenance - can reduce SSI benefits by as much as \$250 a month. "For many people, Medicaid is tied to SSI, which would mean they'd also lose their health insurance," Sandoval adds. "The trustee has to be aware of these rules."

Special-needs trust assets also can be used for supplemental items like wheelchairs or ancillary expenses, such as veterinarian bills for a therapy dog.

In cases involving at-fault injuries, settlements or damages might fund a trust. Since the assets are in the injured person's name, use a d4A or "payback" trust - which lets the person qualify for Medicaid while alive, but reimburses the state for services provided after the person's death, using any money remaining in the trust.

Some families are wealthy enough to fund trusts while the parents are still alive, but other people can fund trusts after their deaths with life insurance proceeds. Term life insurance is an option if the disabled child has a shorter life span and will likely die before a parent. If one parent is a full-time caregiver to the child, purchase a 20- or 30-year term policy that lasts through a spouse's retirement date to cover the child's care.

A better choice, if clients can afford it, is a second-to-die life insurance policy. "Second to die doesn't pay out until the second death, so the premiums are less," Ehlert says. "We make the assumption that as long as one parent is alive and well, they'll take care of the supplemental needs. But the minute you're both gone, you need this pot of money."

Many families establishing a trust want to name a family member as trustee, but this is rarely a good idea, advisors say. Even well-meaning relatives might not have the time or financial acumen to handle the trust's administration. "We find that a good solution often is to have co-trustees, a professional and a family member," says Harry Margolis, an estate planning attorney in Boston.

A professional could be a third-party trust company or a planner. Advisors who oversee these trusts must balance immediate needs against the goal of ensuring that there is enough money throughout the disabled client's life.

"If it's not going to be adequate for the life expectancy or financial needs, you're going to want to manage it in a more conservative fashion," says David Canter, executive vice president of practice management at Fidelity Investments. The temptation might be to try to "make up for lost time" with a more aggressive portfolio, but preserving the principal needs to be a higher priority.